Intermountain® Healthcare

Hemochromatosis

What is it?

Hemochromatosis is a condition in which your body absorbs too much iron from the food you eat. Over time, the extra iron builds up in your organs, especially your liver. As the buildup increases, it can lead to serious problems, including liver disease, pain, and fatigue. Luckily, treatment usually prevents complications.

What are the symptoms?

In men, symptoms usually show up between age 30 and 50. In women symptoms usually develop later, after age 50. (The reason younger women tend to have fewer symptoms, is that they regularly lose extra iron through menstruation, childbirth, and breastfeeding.)

Symptoms can include:

- Abdominal pain
- Fatigue, low energy, or weakness
- Darkening of the skin (sometimes called bronzing)
- Joint pain
- Loss of body hair
- Weight loss

What causes it?

Doctors don't know exactly what causes hemochromatosis. The do know, however, that it is inherited, and it is fairly common. It affects about 5 in every 1,000 people in the United States, although some don't know they have it. It's most common in white people of western European descent. Family members of people with hemochromatosis should be tested to see if they have it.

How is it diagnosed?

Hemochromatosis is often diagnosed before symptoms develop, because it can show up on routine blood tests. Many people also undergo testing after a family member has been diagnosed. Tests to show if you have the disease, and if you already have complications, can include:

- Blood tests to show iron and certain proteins in the blood
- Physical examination to look for swelling of the liver or spleen, and changes in skin color
- Tests for blood sugar, protein, heart function, and liver function
- Imaging tests such as CT scans, MRI, or ultrasound
- Liver biopsy
- Genetic tests

What happens if it goes untreated?

If hemochromatosis is not treated, iron can build up in body organs and lead to severe organ damage. This increases your risk for:

- Liver disease (fibrosis or cirrhosis)
- Liver cancer
- Bacterial infections
- Severe fatigue

It may also increase your risk for other conditions:

- Diabetes
- Arthritis
- Heart disease
- Thyroid disease
- Changes in skin color
- Loss of sex drive

How is it treated?

The goal of treatment is to lower the amount of iron in your body. Hemochromatosis can be treated easily and effectively with blood donation (also called **phlebotomy**). A certain amount of blood is removed from the body each week until the iron level becomes normal. Once your iron levels are more normal, blood will be removed less often.

If you've developed complications from hemochromatosis, they will also be treated. For example, testosterone hormone therapy can help improve loss of sexual desire and changes in testicles. Other treatments may address diabetes arthritis, liver failure, or heart failure.

What can I do?

The most important thing you can do is to stay in touch with your doctor and follow your recommended treatments.

In addition, you need to think about what you eat. It's okay to eat a normal healthy diet. There is no evidence that the condition is made worse by eating a moderate amount of foods with iron. However, you do need to follow these steps:

- **Don't take vitamins or supplements containing iron.** Don't eat cereals fortified with iron. Your doctor may also ask you to avoid vitamin C supplements, because they promote iron absorption.
- **Be careful about alcohol.** Alcohol increases the risk of cirrhosis of the liver. If your liver is okay, don't drink more than two alcoholic beverages a day. If you already have liver disease, don't drink any alcohol at all.
- **Don't eat raw seafood.** It may contain bacteria that grows well in an iron-rich environment.

Should my family members be tested?

Yes. If you have been diagnosed with hemochromatosis, members of your biological family should be tested. If they know they have the disease they can get simple treatments and prevent serious disease.

When should I call my doctor?

Call your doctor if you develop any of the symptoms listed on the first page of this fact sheet.

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